TOPLINE NOTES | June 30, 2004

(An outline of the key points from the meeting participants)

1. **What do you think of the EPHT effort overall?**

Positive:

- Impressive effort
- Ambitious
- Future oriented
- Diverse—planting 1,000 flowers (i.e., initiating demonstration projects)
- Resources have been devoted
- Absolutely needed

Concerns:

- Not enough resources or resource commitment, and concerns about sustainability
- Because CDC may be reinventing prior or current efforts, we need to engage the environmental epidemiology community more.
- Concerns about transitioning from state-based efforts to a national effort
    - Ensuring compatibility across states
    - Establishing national indicators
- Sense of disconnection by nongovernmental organizations (NGOs), community-based organizations (CBOs), and unfunded states
- Worry if CDC and its partners will ever be able to link environmental data to health outcomes
- Tendency to view the partners as only users and not contributors. They want to be involved!

2. **What is missing or unclear?**

- True community participation and leadership; sense that it is citizen-driven; sense that community has been defined broadly
- A plan for moving from baby steps to full system/plan to move from individual state efforts to “national” network
- Adequate funding
- Clarity on how to feed/meet needs of national program and the community/local level
- Tools and standardized components may force all into a cookie-cutter approach and miss or leave unmet the diverse needs.

- Effective communication across and up/down
- Data structures reflect the same "silo" thinking that the Environmental Public Health Tracking (EPHT) programs are in.
- Plan to show what the system can do, but also plan to set appropriate expectations about what it can't do.
- Effective inclusion of state health labs in the process

3. What are areas of overlap or common mission?

- The meeting participants need EPHT information to use for health education and promotion.
- The partners need EPHT information to use for policy and advocacy.
- Committed to
    - Citizen-driven effort
    - Moving beyond data collection and dissemination to real use
    - Having an impact on health outcomes
    - Getting labs involved
    - Data/solid science
    - Bridging the environmental health/public health gap
- CDC and its partners all need to educate all players.
- Common desire for success of the system
- Common fear that failure to show quick payoffs will hurt us

4. What do you need to get from the EPHT Network?

- Scalable system
- Able to make causal links
- Able to use for policy development
- Inclusion of all states
- Better characterization of things like who is exposed, symptoms, etc.—things that preceded health outcomes
- Greater data accessibility, standardization of case definitions and terms such as "epidemic," methods, and improvements in data reliability and usability
- Ability to get at behaviors
- Ability to share/link/integrate data
- CDC/NCEH commitment to listening
- CDC/Office of the Director (OD) commitment to sustaining EPHT
- User-friendly dissemination of information
- Involvement of technical experts from the environmental agencies and disease-specific public health programs
- Inclusion of marginalized communities in the process

- Inclusion of mechanisms for feedback—are CDC's partners getting the right information?
- Ability to share data with users in raw form and not just in report form
- Vision of how the CDC-funded state and local programs will move from 1,000 disconnected flowers (demonstration projects) to garden (integrated system)
- Justification that persuades us and can also be used by us with skeptics
- Ability to mine data at specific community level (i.e., south Philadelphia)
- Ability to zoom-in at census track level
- Ability to use for hypotheses generation; details of who, why, how, where
- Way to provide clear "lay person" understanding of the underlying science
- Ability to act as a data clearinghouse that
    - is a directory to existing data,
    - is tiered, based on data quality and other parameters,
    - includes historical data, and
    - places responsibility for adding and updating information on the data collector
- Ability to detect when environmental agents or diseases exceed a critical level ("red flags"), and availability of a multidisciplinary response team to intervene
- An advisory group for partners
- Timely/real-time results
- Technical assistance to communities about how to implement EPHT and use the data
- Capacity building and training to develop workforce
- Funding

5. What you need to get from the system—specific issue/content areas:

- Indoor air quality and outdoor air quality
- Food safety
- Hazard data useful to public health
- Biomonitoring data
- Asthma
- Neurodevelopmental disorders
- Neurodegenerative disorders
- Autoimmune disorders
- Cancer

6. How do you get information now?

- Very piecemeal, and you need to know where it is to find it
- Often required to go to multiple sources for environmental health information
- All information is reactive.
- Better access to environmental conditions than health

- Sometimes:
  - No data
  - Poor quality data
  - Different data can give you different answers depending on quality.
  - Data case definition for health outcomes not consistent
- Some information comes from community members.
- Use local organization information
- Get information from patients and doctors
- Use census data

7. What do you most need short term?

- Forums/mechanisms to get the environmental health/public health dialogue going
- Assessing/identifying current usable data sources (for example through a data clearinghouse)
- Optimizing use and acquisition of the data CDC has
- Identification and description of all current state/local EPHT advisory boards
- Better connection with unfunded states
- Third party data sets
- Mandates from leadership levels to get disease experts involved in the EPHT effort
- Mandates from funding agencies that require funded programs to work with others, build bridges, etc.
- Models that CDC and its partners can use immediately
- Guidelines on exposure assessments
- Clarity on national priorities
- Training/capacity building of workforce, especially on how to start the environmental health/public health bridge building
- Improved coordination among bioterrorism, tracking, and biomonitoring programs
- Accessible, non-computer tools
- Sharing of best practices
- Completed development of the environmental public health indicators
- Content/issue areas:
  - Occupational exposure data
  - NASA data
  - Data on indoor air quality or role of indoor air quality in this system
- CDC's long- and short-term strategic vision
  - Vision/goals/direction for the nation program
- Information on what the states are doing

8. **How can CDC best communicate with you?**
   - Electronic communication channels (video, Web site, E-mail, listserv, newsletter)
   - Regular forums/meetings
   - Workshops
   - Point of contact for community organizations to work with CDC
   - Use varied and enough channels that CDC will reach tipping point where informal networks for sharing are created.
   - Use NGOs to get information out to constituents.
   - Charge states with bringing people to table.
   - Also, do not forget creating mechanisms for partners to get information to CDC, not just one-way communication.
   - What content you need in communication:
     - Local health departments need information on risk communication
     - What is being planned for next phase
     - More information on other state EPHT efforts
     - More communication to policymakers

9. **How would you like to be involved?**
   - Finding role for unfunded states
   - Advocating for next phase
   - Evaluating efforts
   - Translating environmental data for use by public health
   - Providing input on the developmental process
   - Focusing on involving
     - CBOs
     - Unfunded states
     - Centers of Excellence
   - Using existing meetings well to spread and advance the EPHT agenda
   - Using CDC partners to reach their constituencies
     - NGOs
     - CBOs
   - The partners have specific expertise they are ready and willing to use to support EPHT

10. **Who needs to be at the table that CDC has not already involved?**
    - The “right” environmental health people—move beyond the environmental health “information technology” staff to include the environmental scientists as well.
    - State EPAs
    - GIS experts
    - Information technology
    - Unfunded states

- Health care providers
- Tribal governments
- Environmental justice community
- School districts
- Medicaid/Medicare
- International experts
- Other federal agencies, including National Institutes of Health and United States Geological Survey
- Health insurance payers
- Home insurance payers
- Communities of color
- Marginalized communities
- Labor unions
- Policymakers from all levels and branches of government
    - Legislators
    - National Governors Association (NGA)
    - National Conference of State Legislators (NCSL)
    - Congressional staff
    - United States Conference of Mayors (USCM)
    - National Association of Counties (NACo)
- Industrial hygienists
- State and local air quality folks
- Faith community
- Pharmacy chains
- Poison control
- Pediatric Certified Nurse Practitioners
- Industry

11. Who needs to be at the table that CDC has not already involved—specific organizations?

- NGA
- NCSL
- USCM
- NACo
- Collaborative on Health and the Environment
- Environmental Defense Fund
- Sierra Club
- Children's Environmental Health Network
- Pesticide Action Network
- Professional association for heating ventilation and air conditioning contractors

- Disease-specific nongovernmental organizations
- Learning disability community
- American Medical Association/Association of Medical Schools
- American Public Health Association, Environment Section
- Specific government agencies
    - National Institutes of Health
    - Department of Defense/Veterans Affairs
    - Occupational Safety and Health Administration
    - Food and Drug Administration (FDA)
    - U.S. Department of Agriculture (USDA)
    - State-based Medicaid
    - Centers for Medicare & Medicaid Services
    - Department of Education